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ABSTRACT

The course of psychosocial adjustment to cancer was examined in 105 adults with cancer of the lung, breast and skin. Half of the patients received a program of systematic psychosocial rehabilitation plus evaluation, and the other half received only an evaluation, consisting of a series of psychometric instruments and a problem-oriented structured clinical interview. Patients in the intervention group received a comprehensive program of psychosocial services based on individual need. One rehabilitation worker was assigned to each patient, and this worker followed a patient from day of hospital admission through six months after hospital discharge. Results indicate that: (1) different cancer patients experience "peak vulnerability" at different points during the course of their disease; (2) initial psychometric scores can predict the total number of psychosocial problems reported at the end of six months; (3) intervention and control groups differed in that intervention patients were less likely to exhibit "denial" concerning their illness; and (4) intervention patients engaged in more social and recreational activities at the end of the six-month program. (Author)

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THE PSYCHOSOCIAL PROBLEMS OF CANCER PATIENTS: A PROSPECTIVE STUDY[1]

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by

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The Psychosocial Problems of Cancer Patients: A Prospective Study

I. Purpose

There are three purposes to this study:

A. To prospectively examine the course of psychosocial adjustment to cancer;

B. To determine whether a systematic program of psychosocial rehabilitation can effectively ameliorate the psychosocial problems that are secondary to cancer, and, if so, to determine who the program helps and how it helps;

C. To determine whether there is a way of identifying early in the course of their disease (i.e., at hospital admission) those individuals who are likely to have problems in psychosocial adjustment later on (i.e., six months post hospital discharge).

In order to accomplish these objectives, the psychosocial problems of 105 individuals with cancer of the lung, breast and skin (melanoma) were assessed. Forty-five percent of the patients had melanoma, 35% had breast cancer and 20% had lung cancer. Half of the patients received a program of systematic psychosocial rehabilitation plus evaluation, while the remaining patients only received psychosocial evaluation. All patients were followed from the time of their initial hospitalization through six months post hospital discharge. Thus, the investigation focused on the first six months of the disease.

II. Methods and Procedures

A. The Psychosocial Evaluation

The psychosocial evaluation was comprised of two parts. The first part consisted of a series of psychometric instruments including the Multiple Affect Adjective Check List (MAACL) (Zuckerman, 1965), the Langner Psychiatric Impairment Scale (Langner, 1962); the Schedule of Recent Experiences (SRE) (Holmes & Rahe, 1967), People Test (Diller, Gordon, et al, 1969), and Activity Pattern Indicators (API) (Diller, et al, 1978). The second part consisted of a

problem oriented structured clinical interview. The psychometric instruments provided quick quantitative indices of the patient's psychosocial status as well as a quick overview of recent events in the patient's life. These instruments were also used to validate the second part of the evaluation, i.e. the problem oriented structured clinical interview. These interviews provided the patient with the opportunity to acknowledge the presence of any of 122 psychosocial problems. In addition, the patient was asked to report the severity of any reported problem on a ten point scale (1 = mild to 10 = severe). These 122 problems covered eight broad areas of life functioning: dissatisfaction with medical services; physical discomfort; difficulties with activities of daily living; difficulties with family relationships; difficulties with social relationships; intrapsychic problems; finances; and vocational concerns. Psychosocial evaluations (both psychometric instruments and structured interviews) were administered at four points in time; within 48 hours of hospital admission (T1); at hospital discharge (T2); three months post discharge (T3); and six months post discharge (T4).

B. The Program of Psychosocial Services Offered to Patients.

1. Team: All patients in the intervention group were offered a comprehensive program of psychosocial services. Services were provided by a psychosocial team consisting of psychologists and social workers. A psychosocial evaluator conducted the assessment interviews. The team members functioned as "psychosocial rehabilitation workers". No distinction was made between the traditional professional roles of psychologists or social workers. The team trained each other in the areas of non-overlapping skills and provided mutual support in dealing with some of the psychological sequelae to cancer. They were assisted by a consulting psychiatrist. One member of the team had acquired previous training and experience as a nurse and rehabilitation counselor and thus provided a good linkage with referring physicians.

Only one psychosocial worker was assigned to each patient. It was felt that limiting the number of psychosocial service providers would facilitate patient acceptance of the program. In other models of psychosocial service delivery the patient is often confronted with a wide number of purveyors of services. For example, if the patient has a family problem he/she is sent to a social worker. If he/she has an intrapsychic problem he/she is sent to a psychologist. If he/she has a vocational problem, he/she is sent to see a vocational counselor, etc. It was felt that this more conventional model of service delivery would not work well (at least not in acute hospital settings) with cancer patients. Cancer patients, at the point of initial hospitalization, are likely to be upset, anxious, on edge, etc. and, therefore, not open to sharing information and receiving input from multiple sources. Therefore, it was reasoned that having a single psychosocial worker who continued to see the patient over the six month program would be the best method of providing service for the cancer patient.

2. Intervention: Areas of service delivery offered by the psychosocial workers ranged from the minor (e.g., arranging for a service referral to an outside agency) to the complex (e.g. dealing with poor marital relations or miscommunication between physician and patient). All interventions were documented and tracked using problem oriented records (PORs). The POR methodology was developed by the project staff in order to record the specific problems that were treated and the types of interventions that were offered. A classification scheme was developed for coding these interventions. This methodology provided the opportunity for studying the relationship between type of problem and type of treatment offered.

Patients were seen on an individual basis depending on their needs/problems. Most patients were seen at least once a day while in the hospital. After discharge patients were seen depending upon the need, but most were contacted periodically by telephone.

III. Results*

A. For lung and melanoma patients, there were no significant differences between intervention and control patients in the patterns of psychometric test scores that emerged over time. The anxiety and depression scores (MAACL) of intervention and control melanoma patients declined immediately upon discharge (T2). For lung patients (intervention and control), these scores were significantly higher than those reported by the melanoma patients, and they did not decline with the passage of time. In breast intervention patients, anxiety and depression scores significantly declined at discharge (T2). In the control group, these test scores did not decline until three months post discharge (T3). This pattern of psychometric test scores is very similar to the patterns of "peak vulnerability" that have been reported in the literature by Weisman and Worden (1976).

B. At all four time periods, the number of psychosocial problems that were reported and the severity ratings given to these problems were similar in both the intervention and control groups.

C. The T1 psychometric test scores were used to predict the total number of psychosocial problems reported at T4. In both groups a significant multiple correlation emerged. The multiple correlation in the control group was .50, while in the intervention group it was .85. Twenty-five percent of the variance was accounted for in the control group, while 72% was accounted for in the intervention group. Different sets of variables entered into the two multiple regression equations. In the control group, anxiety (MAACL) and the mean number of life change units (SRE - before the patient entered the hospital) were the only two variables that significantly entered into the regression equation. In the intervention group the variables that contributed significant variance included the mean life change units (SRE - before the patient entered

* All differences are significant at the $p < .05$ level.

the hospital), vocational status, the number of friends reported (People Test*), and the hostility score (MAACL). Interestingly, being employed at T1 and reporting at least two friends were correlated with the report of fewer psychosocial problems at T4 in the intervention group. Thus, although the T4 problem sums of the two groups were essentially the same, these sums were differentially predicted by different sets of T1 variables. It seems logical to hypothesize that the individual problems that were making up these problems sums (i.e. the problems reported) were different in both groups. This situation is analogous to the one in which two equivalent WAIS full scale IQ scores are comprised of different subtest scores.

D. This supposition was confirmed in that both groups reported similar problems at T1 but different problems were reported by patients in the intervention and control groups (at T2, T3, T4). It was found, for example, that both intervention and control patients were likely to report dissatisfaction with the overall service delivery system. They were unhappy with their physicians, nurses, aides, etc. In contrast, patients in the intervention group reported fewer communication and intrapsychic problems. In the communication area, they less frequently reported difficulty communicating with physicians and significant others; they had their questions answered more readily and had less difficulty finding out what it was they wanted to know. In the intrapsychic area, they less frequently reported being depressed. There were other problems that were differentially represented in the two groups as well. More specifically, it was found that patients in the intervention group were more likely to report problems that reflected their willingness to acknowledge disease-related experiences. For example, those in the intervention group were more likely to report that they were having side effects of medical treatment and that these side effects were upsetting. Six months post hospital discharge (T4), these intervention patients were significantly more likely to acknowledge having had an illness in the past

* The instructions were to "name all the people you came in contact with or thought about yesterday." The patient is stopped when 15 people are named.

six months, than those patients in the control group (all patients had an illness in the past six months).

When attempting to integrate these findings, what began to emerge was a behavioral definition of "denial". Denial is a concept that is frequently associated with illness. However, it has been a concept that has long evaded measurement. Although denial is often linked with psychodynamic and psychoanalytic theories it is a concept that has been intuited rather than operationalized. The findings indicated that patients in the intervention group were realistically reporting what was happening to them, e.g. they were acurrately reporting the effects of the disease. Those in the control group, however, did not report the presence of the same phenomena. They did not accurately report actual events that were related to disease associated experiences, e.g., they did not report that they were sick. They also did not report that they were having side effects of treatment and they did not as frequently report that they were upset. Those in the control group had many more problems in communicating. They had difficulty in talking to their spouses and friends, reported that talking to their spouses did not help them, and reported that they had questions that were not answered by their physicians. Thus the reporting of events in one group (Intervention) but not the other (Control) can be interpreted as a behavioral manifestation of denial. This is shown by: a) the unreported events that were known to have occurred (i.e. illness and its side effects); b) the equivalence of both groups at T1 in terms of the problems reported and psychometric scores; and c) the equivalence of both groups in terms of the severity of illness and frequency/type of medical treatments received.

E. At the T1, T3 and T4 evaluations, all patients were administered an instrument which surveyed their social/leisure activities. This survey was an early version of the Activity Pattern Indicators developed by the Rehabilitation Indicators Project (Diller et al, 1978). Analysis of the 59 family role, social/leisure

activities and medical and social service activities surveyed by this instrument indicated the following:

1. At T4, patients in the control group were more likely to participate in personal solitary activities at home (such as studying, doing homework for organizations, reading, watching TV, solitary games, resting or napping) than patients in the intervention group.
2. At T4, patients in the intervention group were more likely to participate in social/recreational activities away from home (such as dining out, going to the movies, going to sporting events, visiting museums, etc.) than patients in the control group.
3. Between T1-T4, control group patients decreased the frequency of their contacts with family members while the opposite was true for intervention group patients.

Thus, it would appear that the intervention program facilitated patients' interactions with family members and aided their participation in a diverse set of social/recreational activities.

F. Most research on the effectiveness of psychotherapy and counseling suggests that those patients with fewer difficulties are those who benefit most in treatment. This was found to be true in our study as well.

G. There was a subgroup of individuals in the intervention group who manifested a greater than average number of communication difficulties at T3-T4 but at the same time were reporting disease related events (e.g. side effects of treatment, etc.). Thus, they were "in touch" with the continuing disease related disruptions of their lives while concurrently having difficulty communicating with others. Of interest was the fact that the psychometric scores (depression, hostility) of these individuals rose (T3, T4) as did the number of psychosocial problems (T3, T4) that they reported. Paradoxically, the severity weights that were given to these problems declined (T3, T4). Thus, although these individuals were having more problems, they were not as troubled by them. In effect they were

saying "Yes, so and so is a problem for me, but I'm coping with it." The price that they were paying for this increased ability to cope was manifested in terms of elevated scores on psychometric tests, e.g. anxiety or depression scales. Thus, this subgroup of people was able to acknowledge more problems while at the same time experiencing more anxiety, but apparently these problems were not bothering them as much.

V. Conclusion

Data have been collected on an additional 100 cases (50 more intervention and 50 control patients). This data will be used to cross validate all the findings that have emerged. This validation will provide the opportunity for making more powerful statements about the effects of intervention. Ultimately, the attempt will be made to discern ways of predicting, from the data collected at the initial interview, those people who are likely to have psychosocial difficulties six months post discharge. Analysis of the relationship between the problems presented and the array of interventions offered will lead to the development of educational programs that can be used by other health care providers. The next phase of our work will also involve the study of cancer patients for longer periods of time, working with cancer patients and families, and, eventually, beginning to work with patients with different sites of cancer. In this way it is hoped that the multiple needs of cancer patients will be better understood and met.

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